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ABSTRACT

Children with autism cannot be taught independent and responsible behavior in the way that most "sociable" children are taught, due to their deficits in social interaction and communication. Children with autism must first build trust in order to feel secure and to be able to concentrate on learning new skills and behaviors. Environmental supports needed by the child with autism may include structured, predictable environments and controlled stimuli. Instructional supports include visual mode communication, analysis of individual strengths and interests, and adaptations. Motivation techniques must also be considered. Long-term goals and consistent, positive approaches should be established early so that the person with autism achieves as much independence and responsibility as possible and gains competence in the activities of adult life. (JDD)

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The University Affiliated Program of Indiana

FUNCTIONAL PROGRAMMING FOR PEOPLE WITH AUTISM: A Series . . .

LEARNING TO BE INDEPENDENT and RESPONSIBLE

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by

Nancy Dalrymple

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LEARNING TO BE INDEPENDENT and RESPONSIBLE

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INTRODUCTION

To be independent means that one is free from the influence or control of others. To depend on others means to be assured, supported, and to place trust in others. To be responsible means to be able to answer for one's conduct and obligations and to be able to choose for oneself between right and wrong. To empower implies investing someone with authority and/or legal power. To reinforce implies giving more strength, force or effectiveness to something, some act, or someone. All of these concepts are important to attain, at least to some degree, in order to be a competent adult in our society. Each of these concepts is discussed in child development literature and in the literature regarding quality programming for people with developmental disabilities.

In the United States we value self-reliance and independence. We value self-assurance and responsibility. Yet, throughout the childhood years, adults often expend much energy and time trying to control children. Teachers and parents want to feel that they have children "under control" and people in communities often frown upon parents who allow their children to "be out of control". An "out-of-control" child casts a shadow on the teacher or parent.

Most children conform to the standards and the images adults have for them because they follow the standard models of development. Most children:

- Want to please people who are most important to them.
- Cooperate more with adults who reason with them.
- Model their behavior on the people they love, admire, and whom they see rewarded.
- Learn to understand others through empathy, perception of social cues, role taking, and communication.
- Develop autonomy through many successful experiences.
- Develop embarassment, shame, and guilt when they fail to be like others or as others want them to be.

However, when a child is impaired in the ability to socially interact and communicate, the foundation of learning independent and responsible behavior is shaky and shifting. A child with autism:

- Relates better with objects than people.
- Can not understand social cues.
- May not understand praise or other social reinforcers.
- Can not put self in place of others.
- Does not know whom to model.
- Has problems taking roles, understanding reasoning, and communicating.
- Has problems understanding and expressing emotions.

Therefore, this child can not be taught and related to as most "sociable" children are. This child has needs that tax every adult, sibling, friend, and peer who encounters him/her.

BUILD TRUST

First, dependence on others is the foundation which builds trust. The trusting, dependent relationship of young children must be solid to allow the child to grow into an adult who can function independently in a larger community life. For a person with autism to trust another person requires many consistent, reliable interactions over time. These interactions lead to dependence, but also lead to assurance that needs will be met and that the world will be secure and understandable. Mistrust arises from discomfort, disappointment, and anxiety, as well as the inability to explore, discriminate, and cope with the world.

Because the ability to utilize sensory input and apply situational memory is impaired in children with autism, the parent and teacher become the primary sources to organize environments and learning sequences so the child can cope and understand. Of necessity, this requires intervening with the child differently than with other children. Until the child or adult with autism feels secure and can trust the situation, s/he will not be able to concentrate and learn new skills and behaviors.

ENVIRONMENTAL SUPPORTS

The many needs of the child with autism may build an overdependence through the constant intervening and cuing that is often necessary in initial teaching situations. The reliance on the adult cues provides security for the child and assists the child in screening out stimuli that s/he may not understand. The teaching strategies that are used with children with autism help the child learn from his/her environment and help focus the child for learning.

Because the world is full of surprises, multiple stimuli, and changes, the person with autism learns best when certain elements are controlled. The need for supports in this area varies from individual to individual as well as from day to day for the same individual.

Structure - Structured environments are predictable. Individuals with or without sensory impairments usually function best and most efficiently when they know where to find what they need and what to expect when they enter a building. Remember the confusion and anxiety you feel when a supermarket rearranges aisles or when a familiar highway is closed. Individuals with autism are impaired in their ability to organize and use sensory input and rely heavily on order and routine. They may become very upset when a room is rearranged, when dad turns a different way in the car, or when they change schools or classes. To help with these problems we know that it is best to involve them in the change, to convey plans to them through visual means such as pictures and written words, and to visit new environments repeatedly until they are comfortable.

Sequences - Another aspect of structure and order is the sequence of events. Knowing what is going to happen within each environment and within each day, as well as in the future helps eliminate anxiety and helps a person function better. For a person with autism it helps to establish general sequences that are predictable each day. Some, by necessity will happen at the same time, but others will follow a set order. It also helps a person with autism function better, if the sequences are visually displayed on a daily schedule, a weekly calendar, or an appointment book.

Changes can be concretely shown and the person can be involved in planning the changes.

Routines - The order of steps within an activity establishes the routine for that activity. Most people rely on set routines to get them through much of the day without even realizing it. There is a get-up and get-started routine, an evening routine, and a set routine at banks and restaurants. People with autism rely very heavily on routines and sometimes strongly resist any changes within the routine. If mom is the cue to get up and to dress, there will be strong resistence to changing that. If bath time is after dinner and before bed, or if storytime is before bed, there will be protests to changing this order.

Preparing a person for the change, visually presenting the altered routine, and involving the person in the change by presenting concrete choices may help. It also may help to realize that when a routine is being established, it is wise to consider the ultimate outcome. Set up the learning sequence to encourage independence and harmonious functioning, if at all possible.

Controlled Stimuli - Sometimes it is necessary for the environmental stimuli to be controlled for people with autism. Some situations are impossible for them to handle. There may be too much movement, loud or sudden noise, space, lights, mirrors, crowds, verbal directions, or touching. Usually it depends on what the person is supposed to do in the environment and how much support and experience s/he has had with the situation. Being bombarded with stimuli or being required to deal with particularly difficult stimuli often raises the person's anxiety level and makes coping that much more difficult. Strategies that are effective in learning to manage varying stimuli include:

Order - Knowing where s/he is to stand/sit/move, what will happen and where everything will be helps relieve anxiety.

Time Alone - Knowing there is a place to go to get away and be alone, sometimes gives the person with autism an appropriate way to escape. S/he learns to manage increasing periods of time with others, but has some quiet time to regroup. During time alone the person may engage in some type of sensory activity that is calming and reassuring such as rocking in a chair, swinging, or listening to music.

Desensitization - Becoming familiar with the stimuli over time and in small increments is usually successful. Success and reinforcement must be built in. Slowly increase tolerance to environmental stimuli and stimuli that are frightening or frustrating.

Rehearsal - Rehearsing strategies to implement when s/he needs help to handle situations that are overwhelming allows the person to stay in control. Some of these are:

- asking to leave or take a break,
- asking for help,
- asking to pass in the halls before or after others,
- going to a specified space, and
- making a choice that is offered to change the situation.

Tuning Out - All people use this strategy in times of stress. Sometimes people with autism use it in odd ways and therefore draw attention to themselves. Teaching coping strategies, or things to do when there is no escape or help might be useful.

However, understanding the pacing, twirling, spinning, and flicking behaviors as a reaction to stimuli lets us know that building functional, sensory activities into people's programs is often necessary.

INSTRUCTIONAL SUPPORTS

Because children with autism are often trying very hard to organize conflicting stimuli and confusing information so that they too can succeed, the information must be presented in formats that they can understand and use.

Visual Modes - Much of the information that children and adults are required to learn about is presented through verbal communication using the auditory mode. Communication is impaired for all people with autism. Further, the understanding of social communication cues such as gestures, facial expression, body language, and voice tone is also impaired. Therefore, as a rule of thumb, the more people with autism can be provided with visual cues that are concrete and stable the better they will understand what they are expected to do.

In fact, too many verbal cues add to the confusion. There is often a great deal of verbalization in a given environment. The person with autism may not even know what is directed towards him/her.

Some general rules are:

1) Pair words with visual stimuli such as gestures, objects, activities, pictures, and words.
2) Plan stimulus cues to give the person information about activities and routines rather than constant use of verbal means. (i.e. the gym bag means it is time to go to P.E., the car keys indicate that someone is going to leave, the lunch ticket means it is time for lunch, and setting the table means that it is time to eat.) Often, the person with autism uses stimulus cues to understand what is going to happen, but sometimes misinterprets. For example, if the car keys are the signal that s/he gets to go for a ride, but this time mom goes alone, there is likely to be some sign of confusion on the part of the child.

Strengths - When teaching a person with autism it is important to know the learning styles and the strengths of the person. Sometimes it's necessary to look at deficits in a different way. A good visual memory can be used to strengthen functioning within each day. So often a person with autism seems to remember whole sequences when s/he is in the same situation or when s/he receives the same environmental cues. A person may have good visual patterning skills or good auditory memory. Sometimes the ability to do something over and over in the same way can be capitalized upon and used to perform jobs and activities requiring repetition.

Interests - Build on the interests of the person and find ways to expand and utilize these interests as much as possible. Learning through the visual mode might take place through computers and computer games and might provide the incentive to take turns and share. An interest in basketball might create the motivation to keep statistics and do math. An interest in ice cream might provide the reason to learn to scoop with a spoon.

Adaptations - A variety of adaptations are necessary to ensure success. These may include participating for a limited amount of time, using a step by step check-off list, using a wallet-sized communication book to order food, using templates to understand amounts, using timers to understand the passage of time, or carrying a favorite toy or book to use while having to wait. Individualizaiton and creativity are necessary when analyzing an activity to determine what adaptations will enable a person with autism to function more independently and successfully.

Communication - Understanding directions and comments and expressing wants and needs are essential to everyone. In order to grow toward independence a person has to be able to communicate. Because many people with autism are not able to initiate interaction with others well, it is often thought that they don't want to or don't need to. Usually they are not able to process and organize information in order to use it and express it effectively.

Teaching communication skills must be a first priority throughout the person's life. There must be a consistent, long-term plan that is carefully assessed and monitored as the person grows and changes.

MOTIVATION

Perhaps one of the more difficult areas to understand when teaching children, youth, and adults with autism is how to motivate them to want to do what others do. Perhaps the lack of ability to make good judgements is the reason that so many people with autism become dependent on the presence of adults and dependent on verbal or physical cues to perform. They have learned that they cannot rely on their own judgement, so they wait for cues. Too often they are not aware of time cues, other people's needs, other topics or situations around them, and therefore make poor decisions. It becomes safest to make no decisions and not to act at all. Understanding the importance of preferences and choice making is necessary to understand motivation.

Making a choice is a way to exert one's independence and to exert control over one's world. However, a person can only make a choice if an activity or item is preferred over another and if there is really an opportunity to be rewarded by the choice. Offering too many choices or requiring someone to make choices when that person is unable to do so due to fatigue, confusion, or inexperience may lead to frustration and anger.

How does a person learn to make choices? How does a person even understand the concept of choice making? A person learns to make choices:

- through a desire to exert control over one's environment.
- through experiences with people, objects, activities, and foods that are successful and pleasurable so there is motivation to prefer one over the other.
- through successfully being reinforced by getting what one desires.
- through the development of a communication system that allows the person to understand that a choice is offered, understand what the options are, and have an acceptable way to indicate a choice.
- through negotiation.

Where does the concept of choice become confused for a person with autism?

First, the person must want to exert some control and must reach out to gain that control. The first attempts at exerting preferences may be to reach out and explore. If the world is too confusing the child may find ways to close himself in and entertain himself with repetitive body movements or repetitive movements with objects; or the child may exert control by refusing. If the world is too confusing one way to preserve oneself is to refuse to participate. Therefore, in order for individuals with autism to have the motivation to make choices requires that they have successful experiences that encourage them to develop preferences and control.

A person with autism then needs to understand that there is a choice. The first choice making probably will be in the form

of taking or doing what one wants to do without anything being offered or anyone being asked. If the child is hungry, he gets some bread. If he wants to go outside, he goes out and runs. When the person with autism makes these initiations s/he is often reprimanded and the experience of initiating and choice making becomes something to avoid or s/he "tunes-out" the negative and impulsively does as s/he desires.

Sometimes the individual prefers to get something for himself rather than have to go through another person. So s/he exercises the right to make choices by doing something, but in reality part of the motivation for initiating on his/her own is to avoid interacting with others.

Next, the person is required to understand that a choice is being offered, and what the options are. Beyond that, the person must have an acceptable way to indicate the preference so that others understand. The strategies that the person used for self initiation of choice making may not be acceptable, allowed, or understood.

How can the person with autism understand that a choice is being offered?

- Start with the items in view.
- Indicate each by gestures and verbalizations.
- Always use the same vocabulary.
- Provide a visual means of making a choice by using pictures, symbols, words, and/or objects.
- Combine words with gestures and visual materials when possible. The word "or" may not be understood or heard, therefore, only the last word is heard, or only part of the sentence is understood.
- The final step in understanding choice making is to receive the choice that is made; experience the choice. The person is more likely to be motivated to make choices and learn to exert control appropriately if it matters to him/her.

Reinforcement - Reinforcement can be built into naturally occuring sequences by using cause and effect events. Sometimes cause and effect has to be demonstrated through naturally occurring experiences. Examples are:

- Take off the paper, then use the straw.
- Turn on the water, then get a drink.
- Go up the rope tow, then ski down.
- Put on your coat, then go outside.

Contingencies can then be used in teaching sequences to reinforce participation in a less desirable activity.

- Take a bite of meat, then a drink of milk.
- Go visit the doctor, then get an ice cream cone.
- Work quietly, then listen to music.

Daily schedules can be designed to include preferred activities throughout the day. Vary new activities with familiar, acquired activities to increase motivation.

Utilize activities that are preferred and of interest to teach concepts and skills. An interest in basketball can be used in math, reading, conversation skills, spatial and sensory skills and social interaction. Develop interests and perseverations rather than try to extinguish them, and use them when possible.

Familiar activities become preferred if the person has been successful at doing them. Initiation and attempts must receive positive reinforcement in order to build confidence to try again or keep trying. Failure, fear, criticism, and negation lead to lack of motivation and initiation.

Token systems and contracts can be used to give people with autism a reason to do what they are expected to do. They must understand the connection between the behavior and the outcome and be rewarded with preferred activities/items of choice. As much control as possible for monitoring and managing the plans should be given to the learner.

EXPANDING AND TEACHING SOCIAL INTERACTION

People with autism have to be taught how to interact appropriately with others. Too often they are expected to

respond to the "social rules", or "Mom and Dad's rules" without being taught what the expectations are. Waiting, initiating, sharing, taking turns, being quiet, being modest, understanding body language, imitating, understanding humor and teasing, and honoring other people's personal space are just a few of the social concepts that require the understanding of a complex set of stimuli. Pressure to conform, be part of a group or crowd, or follow rigid social rules without instruction, reinforcement, support, and interpretation can lead to frustration and failure. Repeated failure can lead to depression and loss of initiative.

Peer tutors and advocates are excellent teachers of social skills if they receive support and training. Repeated practice using social skills and applying social rules to a variety of specific environments will enhance learning. Social events are not reinforcing until the person with autism has learned the expectations, become accustomed to the stimuli, and feels secure and relaxed.

Eating out, playing video games, going to concerts, or swimming may become reinforcing for reasons other than the enjoyment of being with others. Forcing too many social expectations may create anxiety and avoidance.

SUMMARY

To become a responsible, independent adult requires the development of trust in others and in the environment. This trust grows through successful interactions. Individualized, supportive programs with positive teaching strategies help the person with autism learn the functional skills and behaviors needed in adult life. This growth toward independence and responsibility must be planned carefully; and every step, however small, must be appreciated. Long-term goals and consistent, positive approaches should be established early so that the person with autism achieves as much independence and responsibility as possible and gains competence in the activities of adult life. Empower people with autism by giving them the tools they need to become independent and responsible people.